Acceptance and Quality of Life in Individuals with Chronic Pain

BY

LINDSAY BARAN B.S., University of Illinois at Urbana-Champaign, 2005

THESIS

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Chicago, Illinois

Defense Committee:

Fabricio Balcazar, Chair and Advisor Glenn Fujiura Diana Wilkie, Nursing

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LIST OF ABBREVIATIONS

ACT Acceptance and Commitment Therapy

CPAQ Chronic Pain Acceptance Questionnaire

IASP International Association for the Study of Pain

IOM Institute of Medicine

PCS Pain Catastrophizing Scale

PHQ-9 Patient Health Questionnaire 9-Item Depression Scale

QOL Quality of Life

WHO World Health Organization

WHOQOL-BREF World Health Organization Quality of Life Assessment- Brief

version

SUMMARY

Several studies have suggested that there may be a positive correlation between acceptance of pain and quality of life (QOL). The purpose of this research was to find out whether acceptance has an impact on the QOL of individuals with chronic pain.

Current levels of acceptance and QOL were established by having participants complete an online survey, which included the World Health Organization Quality of Life Assessment-Brief version (WHOQOL-BREF) and the Chronic Pain Acceptance Questionnaire (CPAQ). Other variables were also measured, including depression, catastrophizing, pain level, pain duration, and other demographic characteristics.

Participants were recruited through various chronic pain organizations, and four hundred and sixty individuals completed the survey. Results confirmed a strong positive correlation between acceptance of pain and QOL. Because these findings illustrate that acceptance of pain may play a critical role in the lives of people with chronic pain, it is necessary to further explore the incorporation of acceptance-based approaches to chronic pain management.

Keywords: Chronic pain, acceptance, quality of life

I. INTRODUCTION

Experiencing chronic pain can interfere with an individual's quality of life (QOL), however many studies suggest that this may be an indirect relationship, stating that the presence of pain alone cannot determine how great that impact will be. Several studies have suggested that there may be a positive correlation between acceptance of pain—with acceptance entailing giving up unsuccessful attempts to control pain and focusing instead on participation in valued activities—and QOL.

The purpose of this study is to determine whether acceptance of pain impacts the QOL of individuals with chronic pain. Current levels of acceptance and QOL will be established by having participants complete the Chronic Pain Acceptance Questionnaire-Revised (CPAQ) and the World Health Organization Quality of Life- BREF (WHOQOL-BREF). Scores will be correlated to determine if there is in fact a relationship between acceptance level and QOL.

Results of this study will hopefully lead to further research on acceptance of chronic pain and QOL. Additionally, results from the study can potentially help practitioners and professionals focusing on chronic pain to better understand the role of acceptance in chronic pain management.

II. LITERATURE REVIEW

A. Chronic Pain

The International Association for the Study of Pain (IASP) defines pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (Merskey & Bogduk, 1994, p. 210). Pain is part of the human condition, but it is generally thought of as a temporary sensation. When pain persists beyond the expected course of a disease process, or for a period longer than 6 months, it is considered chronic pain (Russo & Brose, 1998). Chronic pain is commonly triggered by an initial injury or disease, but for known or unknown reasons the pain may continue beyond the normal timeline. This could be because "the injury may exceed the body's capability for healing, because of the loss of the body part, the extensiveness of the trauma and subsequent scarring, or...the nervous system may be damaged by the original injury in such a way as to be unable to restore itself to a normal state" (Loeser & Melzack, 1999, p. 1609).

A more specific definition of chronic (nonmalignant) pain was proposed by Dunajcik (1999) as "pain that has lasted 6 months or longer, is ongoing, is due to non-life-threatening causes, has not responded to currently available treatment methods, and may continue for the remainder of the patient's life" (p. 471). While by definition, chronic pain differs from acute pain primarily in its duration, Hilbert (1984) suggests that the pain's chronicity "fundamentally alters the entire experience, especially the sufferer's conception of the infliction" (p. 367). Therefore, a person with chronic pain is not going through the same 'pain experience' as someone dealing with acute pain. Expanding on this idea, Loeser and Melzack (1999) stated that "because chronic pain is unrelenting, it is

likely that stress, environmental, and affective factors may be superimposed on the original damaged tissue and contribute to the intensity and persistence of the pain...the cause of a person's perception of pain may persist irrespective of medical treatments" (p. 1609).

When pain turns chronic, individuals must learn how to navigate their lives while simultaneously managing their pain. The pain characteristics of people with chronic pain vary- the pain can be constant or intermittent, it can be in one or multiple locations, it can encompass a variety of sensations (burning, throbbing, stabbing), and it can range from mild to excruciating (Gerstle, All, & Wallace, 2001)-- but in all cases, the pain is long-lasting. This becomes exceedingly difficult since chronic pain serves as "a somatic reminder that things are not right...this reminder, phenomenally situated in one's own body, is inescapable" (Hilbert, 1984, p. 370). While individuals dealing with other concerns-- health-related or not-- are likely able to 'forget about their troubles' for periods of time, the persistence of chronic pain prevents individuals dealing with it from achieving any amount of reprieve.

It has been well documented that pain is interruptive and distracting (Crombez, Eccleston, Baeyens, & Eelen, 1996, 1997; Eccleston & Crombez, 1999). Basbaum and Jessell (2000) stated that the sensations often associated with pain are "the most distinctive of the sensory modalities. Unlike...vision, hearing and smell, pain has an urgent and primitive quality, a quality responsible for the affective and emotional aspect of pain perception" (p. 472-473). Biologically, pain is a signal of danger to the body, so it demands attention by interrupting other ongoing mental processes to warn against harm. One might assume that over time, the body would adjust to this ongoing signal or

that the brain would be able to shift its focus after recognizing that no further danger is approaching. This is not the case. Pain is difficult to disengage from-- whether it is acute or chronic-- and chronic pain becomes a chronic distraction that adds to the disabling nature of the pain itself (Crombez et al., 1996).

Recent research has more consistently started viewing chronic pain as a disease in its own right, which makes it more important than ever that pain be studied and better understood. There are still some physicians and researchers who hold the view that pain is always a symptom and should not merit its own medical diagnosis (Berger, 2000). However, it is widely understood that chronic pain has many components, including the actual damage or cause of the pain, as well as psychosocial, behavioral, and psychological factors (Turk, 1999). The Institute of Medicine's (IOM) (2011) study published by the Committee on Advancing Pain Research, Care, and Education explains that "chronic pain has a distinct pathology, causing changes throughout the nervous system that often worsen over time. It has significant psychological and cognitive correlates and can constitute a serious, separate disease entity" (p. 1-4).

In an editorial about the European Federation of the IASP Chapters' (EFIC) "Declaration of Pain", Niv and Devor (2004) delve into the multiple underlying issues that lend to chronic pain being considered a disease. Some of the reasons stated include: chronic pain induces consistent physical and psychosocial changes (such as depression, disability, and disturbed sleep), which could be considered 'symptoms' of chronic pain disease; chronic pain does not tend to resolve itself-- rather, it tends to persist over the course of years, and conditions that last for years are generally considered disease states; and science is making progress in understanding the neurobiological basis for some

chronic pain states, including changes in neural functioning and specific tissue pathophysiologies. Chronic pain has even been shown to change brain activity, activating certain brain structures (such as the periaqueductal gray matter, which are involved in such functions as blood pressure regulation and respiration) and decreasing activity in other areas (such as the thalamus) (Siddall & Cousins, 2004).

Unfortunately, there still isn't a clear idea about how to address the growing problem of chronic pain. According to the IOM, "many health care providers lack a comprehensive perspective on pain and not infrequently interpret the suffering of others through their own personal lens. Misjudgment or failure to understand the nature and depths of pain can be associated with serious consequences-- more pain and suffering-for individuals and our society" (2011, p. x). In a 2007 survey of internal medicine residents, 64% of respondents rated their preparation for helping patients with chronic pain as "fair" or "poor" (Chen, Fagan, Diaz, & Reinert, 2007). Respondents found chronic pain management unrewarding and reported negative experiences in working with patients with chronic pain, in addition to feeling uncertain about pain diagnoses. This is not surprising considering the data on pain education in medical schools. In a study of 117 U.S. and Canadian medical schools, only 17 of the 104 U.S. schools offered a designated pain elective, and only eight of these offered more than one (Mezei & Murinson, 2011). On average, a total of only nine hours was spent on pain topics in the U.S. schools.

According to the IOM's report (2011), chronic pain conditions affect at least 100 million U.S. adults. There is considerable debate about the prevalence of chronic pain, with reports ranging from 11% to 64% of the population. However, the IOM's estimate

is widely accepted and other recent studies have reported similar numbers (Johannes, Le, Zhou, Johnston, & Dworkin, 2010; Landmark, Romundstad, Dale, Borchgrevink, & Kaasa, 2012). Chronic pain conditions cost from 560 to 635 billion dollars each year in treatment and lost productivity (IOM, 2011, p. S-1). Chronic pain disrupts thousands of lives each year, and individuals with chronic pain are increasingly unable to meet role expectations due to functional limitations (Rucker, Meltzer, & Kregel, 1996). In 2000, pain was reported to be the second most common reason for seeking medical care, resulting in over 80 million physician visits in the U.S. annually (Berger, 2000). Further, because of the wide variety of causes, including – an underlying disease or medical condition, an injury, medical treatment (for example, after surgery), inflammation, neuropathic pain, and unknown causes – nearly everyone will experience pain at some point, and each of them have a chance of developing pain that is chronic (IOM, 2011).

1. Musculoskeletal pain

More people experience musculoskeletal pain than any other category of pain (IASP, 2009a). Musculoskeletal pain includes a wide variety of diseases, disorders, and injuries that cause pain in bones, joints, muscles, or surrounding structures (IASP, 2009b). Common musculoskeletal conditions are low back pain, neck pain, other joint pain, tendonitis, limb pain, arthritis, osteoporosis, fibromyalgia, myofascial pain syndrome, tunnel syndromes, and neuropathies (IASP, 2009a; IASP, 2009b).

According to the U.S. Bone and Joint Initiative (2011), musculoskeletal disorders and diseases are the most common conditions in the country, and they are the leading cause of chronic pain and physical disability. According to a National Center for Health Statistics National Health Interview Survey, of the four most common medical conditions

reported in 2008, three were musculoskeletal conditions: low back pain, chronic joint pain, and arthritis (U.S. Bone and Joint Initiative, 2011).

B. Quality of Life

Pain is typically discussed as a physical concern, but it can also have an impact on nearly every other aspect of life, thereby decreasing general well-being (All, Fried, & Wallace, 2000; Katz, 2002). Pain is commonly acknowledged as one of the most important determinants of QOL (Katz, 2002). The World Health Organization (WHO) defines QOL as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHO, 1997).

It is a broad ranging concept incorporating in a complex way the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of the environment. This definition reflects the view that quality of life refers to a subjective evaluation, which is embedded in a cultural, social and environmental context. As such, quality of life cannot be simply equated with the terms "health status", "life style", "life satisfaction", "mental state", or "well-being". Rather, it is a multidimensional concept incorporating the individual's perception of these and other aspects of life. (WHO, 1999, p. 3)

Chronic pain has been shown to affect physical, emotional, social, familial, and occupational functioning (Siddall & Cousins, 2004), and has been shown to reduce QOL more than almost any other condition (Donaldson, 2008). Often, this is not only a result of the pain itself, but also of the pain-related problems and stressors that a person with

chronic pain will experience (Dysvik, Natvig, Eikeland, & Lindstrong, 2005; McCracken & Zhao-O'Brien, 2010). Pain can produce anxiety and emotional distress, interfere with functional capacity, and hinder the ability to fill family, social, and vocational roles (Katz, 2002). Donaldson (2008) states "Pain often becomes intertwined with the lives of people living it. Pain has been described as 'exhausting' and 'mentally draining', and the experience of living with it 'frustrating', 'isolating' and 'humiliating'" (p. 35).

Haraldseid (2012) asserts that many of the problems associated with pain are in part due to the many losses that people with chronic pain experience.

A major finding in the present study was that all participants lost their ability to engage in activities that were important and meaningful for them. This seemed to influence their well-being and caused them to experience loss...Participants reported that loss of employment contributed to loss of identity, meaning, and self-worth, leaving them feeling unwanted by society...Interpersonal relations may suffer from the lack of mutual understanding, which causes the relationship to come to a halt...In addition...The personal changes caused by chronic pain seemed to make them become different in mood, thoughts, behavior, and feelings of self. (p. 5)

In addition to the major losses chronic pain causes, the inability to do simple activities is also notable. Breivik, Collett, Ventafridda, Cohen, and Gallacher (2006) found that many people with chronic pain were less able or unable to do a range of activities such as sleep, walking, having sex, and doing household chores. In fact, activity engagement has been found to be a significant predictor of severity of depression in individuals with chronic pain (Nicholas & Asghari, 2006). Miles, Curran, Pearce, and Allan (2005) found that the

inability to do simple activities, specifically those that previously required no forethought, may have just as much of an impact on a person's view of oneself and on their QOL. "The small-scale changes often indicate a fundamental challenge to people's everyday reality, through altering taken-for-granted aspects of their world" (Miles et al., 2005, p. 440).

A life with chronic pain is full of constraints, which Miles et al. (2005) categorized under one of three main areas: bodily constraint, which includes the speed at which individuals could get things done, the limitations to their social world, the split between mind and body (due to the amount of forethought nearly any activity requires for a person with chronic pain), and the loss of comfort, activity constraint, and identity constraint, which includes actions and judgments of other people, one's own ability to do things, physical changes, and the surrounding environment. These constraints often lead to an evaluation of the impact of pain by comparing oneself to others and to one's former self, and they strongly influence a person's coping style. Murphy and Fischer (1983) described this conflict as "a struggle toward *continuation* of one's way of being – one's values, identity, sense of self. The struggle is to be true to one's past, to sustain it in the present and to project it into the future" (p. 294).

However, these losses and constraints make a 'continuation of one's way of being' impossible for many individuals with chronic pain. These limitations, which are often inherently part of the chronic pain experience, clearly may have an impact on the domains of QOL set forth by the WHO, which are: physical domain, psychological domain, levels of independence, social relationships, environment (including factors such as financial resources, safety and security, transport, and accessibility and quality of

health and social care), and spiritual domain (WHO, 1999). Improving QOL is an important goal, and QOL outcomes are especially relevant in the case of chronic pain where complete recovery is not possible (Ainger, Forster-Streffleur, Prause, Freidl, Weiss, & Bach, 2006; Skevington, Carse, Williams, 2001).

1. Research on quality of life

There are many studies illustrating a reduced QOL in people with chronic pain. Becker et al. (1997) reported a multidimensional reduction in health-related QOL in patients with chronic pain, with similarly severe impairments in physical, social and psychological well-being as seen in patients with severe cardiopulmonary diseases or major depression. Kerr, Fairbrother, Crawford, Hogg, Fairbrother, and Khor (2004) reported "profound health status limitations" and an "exceedingly low quality of life" in chronic pain clinic attendees (p. 407-408). Lame, Peters, Vlaeyen, Kleef, and Patijn (2005) found chronic pain patients at an outpatient pain clinic to be experiencing "strikingly low quality of life" (p. 15). Fredheim et al. (2008) found that individuals with chronic pain reported lower global QOL and cognitive functioning, higher sleep disturbances and financial difficulties, and equally poor physical, social, and emotional functioning than palliative cancer patients.

In Breivik et al.'s (2006) study, one-third of participants "said that they were less able or unable to maintain an independent lifestyle and two-fifths of people said that their pain made them feel helpless and they could not function normally" (p.310). Hitchcock, Ferrell, and McCaffery (1994) surveyed individuals with chronic pain who were members of a national self-help group and found that 71% reported that pain affected their personal relationships, 87% reported that pain interfered significantly with normal

activities, and 69% reported that they at times feel hopeless about their pain problem, with 50% having at some point considered suicide.

In inspecting the means for the pain and discomfort facet of the World Health Organization Quality of Life assessment (WHOQOL-100) of pain patients compared with individuals without pain, Skevington (1998) found that "Quality of life is good for those who are pain-free, poorer for those in acute pain, and poor for those in chronic pain...Pain and discomfort are found to be of great importance in the subjective assessment of quality of life, and its presence or absence are found to make a difference to the way people respond to questions about many areas of their quality of life" (p. 402).

2. **Assessment of quality of life**

In the past, there has been some confusion as to what QOL actually entails. Researchers often have used terms such as 'health status' or 'well-being' interchangeably with 'quality of life' (All et al., 2000; Gill & Feinstein, 1994), when in reality, QOL is a much broader construct. Gill and Feinstein (2004), in discussions with other clinicians, believed that general (or global) QOL should reflect the way a patient perceives and reacts to his/her health status along with other, nonmedical aspects of his/her life. Health-related QOL measures tend to be more focused and more limited than instruments measuring global QOL (Niv & Kreitler, 2001). Therefore, while instruments aimed at measuring health-related QOL are sufficient for indicating health status, it is also important to know how satisfied people are with health-related and non-health-related aspects of their lives (Skevington, Sartorius, & Amir, 2004). The incorporation of subjective information, such as individuals' values, preferences, and feelings, ensures that global QOL is being measured (Gill & Feinstein, 1994).

One of the major problems with measuring health-related QOL is that all aspects of life, not just health-related issues, have the potential to influence perception of QOL (Lawson, 1999). Additionally, level of impairment does not necessarily imply reduced QOL (Abramson, 1996; Albrecht & Devlieger, 1999; Johnson, Amtmann, Yorkston, Klasner, & Kuehn, 2004; Lee, Chronister, & Bishop, 2008). People may have many functional limitations (and thus, a relatively low objective health-related QOL), but they may successfully adapt and cope in order to live a personally satisfying life (and thus, have a relatively high subjective QOL), and vice versa (Huang, Wu, & Frangakis, 2006). It's also known that the negative effects of pain go beyond that which can be measured through health reports, and that people perceive these negative effects differently, which is why the subjective nature of QOL measurements is so relevant. Measuring QOL allows us to look at the impact of health and pain within the broader spectrum of life (Lawton, 1999).

C. Acceptance of Pain

Shortly after a person is diagnosed with chronic pain, they will likely be told that they must learn to live with the pain. They must then reframe everything they knew about pain and figure out how to embark upon this new life experience. While it is generally accepted for people experiencing acute pain to express their pain, to withdraw from 'normal' life for a while, or to display signs of fatigue or moodiness attributed to the pain, people whose pain becomes chronic are expected to learn to manage it appropriately (Hilbert, 1984). As Hilbert explained,

When pain is chronic, one might expect the appropriate method of managing it to become chronic also. But when these methods become chronic, they cease to be appropriate. One cannot moan all the time; one cannot confide or expect deferential treatment all the time; one cannot quietly withdraw for the rest of one's life; one cannot even conceal such an object of one's attention all the time.

Thus, culture fails once again to tell sufferers how to handle pain. (1984, p. 370) Our culture and our personal histories inform people how to react to many situations; they do not, however, prepare people to live with chronic pain. Most people learn that the presence of pain signifies the need for a doctor, and that the doctor will fix the problem. The fact that chronic pain cannot be 'fixed' leads many people with pain to continually, and unsuccessfully, seek a cure (McCracken, 1998).

Recent research has begun to identify acceptance as an effective behavioral process that can enable people to live more fully with chronic pain. The idea of acceptance of chronic pain may be counterintuitive; when a person experiences pain, the common-sense reaction is to try to get rid of it. However, in the case of chronic pain, people often make countless efforts to reduce their pain with little or no success.

Moreover, because of the urgent nature of pain, these attempts are often at the expense of many or all other aspects of life, which can significantly reduce overall QOL (Thompson & McCracken, 2011). McCracken, Carson, Eccleston, and Keefe explained,

Somewhat paradoxically, there may be occasions when helpful change in the quality of a patient's life can only occur when some aspects of the problem are accepted as they are...Pain control is, of course, useful when it can be achieved...However, efforts to control pain can be problematic under some circumstances: when they (a) dominate the patient's life and do not succeed, (b) lead to unwanted side effects or complications, and (c) move the pain sufferer

increasingly away from the things that are important to them, such as health, work, friends, and family...If efforts to control pain dominate, quality of living may be sacrificed...Many of the problems of chronic pain may emerge from unhelpful attempts to control or avoid experiences of pain...The alternative to control and avoidance of experiences evaluated as unwanted is to have them as they are or accept them. (2004a, p. 4-5)

Therefore, acceptance as related to chronic pain can be defined as "acknowledging that one has pain, giving up unproductive attempts to control pain, acting as if pain does not necessarily imply disability, and being able to commit one's efforts toward living a satisfying life despite pain" (McCracken, 1998, p. 22). Acceptance is not simply a decision or belief, but rather moment-to-moment choices to change behavior patterns to focus less on controlling the pain and more on other valued life activities (McCracken, Vowles, & Eccleston, 2004b). McCracken (1998) described this as a continuing process of balancing control strategies with acceptance.

While there may be negative connotations of the idea of acceptance as being synonymous with being passive or resigned, the reality is that acceptance can have very positive consequences for people in pain by allowing them to continue living their lives and engage in activities despite the presence of pain (Mason, Mathais, & Skevington, 2008; Thorsell et al., 2011). Acceptance does not mean resigning oneself to suffering, ignoring the pain, thinking about pain as a positive experience, or giving up on effective pain management strategies (McCracken et al., 2004b). Moreover, acceptance is more than just coming to terms with the pain's chronicity. Rather, a goal of accepting chronic pain is reducing its potential to overpower life (Risdon, Eccleston, Crombez, &

McCracken, 2003), or "having these experiences as they are" (Thompson & McCracken, 2011, p. 144).

1. Research on acceptance

There have been quite a few studies examining the impact of acceptance in individuals with chronic pain. McCracken (1998) found that "greater acceptance of pain was associated with reports of lower pain intensity, less pain-related anxiety and avoidance, less depression, less physical and psychosocial disability, more daily uptime, and better work status" (p. 24). A study by McCracken and Eccleston (2003) showed similar results, finding that greater acceptance of chronic pain was associated with less pain, disability, depression, and pain-related anxiety, higher daily uptime, and better work status. In a 2005 study they again found acceptance variables to have a strong relationship with measures of disability, depression, and anxiety (McCracken & Eccleston, 2005). Esteve, Ramirez-Maestre, and Lopez-Martinez (2007) found that while acceptance of pain did not influence reported pain intensity, it determined the variables related to activity (functional status and impairment).

Some studies have focused specifically on the impact of acceptance on mental health. In a study with 66 chronic pain patients, Viane et al. (2003) found greater acceptance of pain to be associated with better mental health, with evidence being found for two core components of acceptance: engagement in normal life activity despite pain, and recognition that cure is unlikely. Another study by Viane et al. (2003) confirmed that acceptance of pain had a moderate and unique contribution in explaining mental well-being.

In a study of acceptance of chronic pain, McCracken, Spertus, Janeck, Sinclair, and Wetzel (1999) found that independent of pain intensity, individuals whose pain affects a broad range of functioning reported less acceptance of their pain and more pain-related anxiety in comparison to individuals who deny significant effects of pain. In 2007, McCracken, Vowels, and Gauntlett-Gilbert found that people with chronic pain who carry on with activity while acknowledging the pain's presence were associated with better physical, psychosocial, and emotional functioning over time, and conversely, attempting to control pain was associated with relatively worse functioning. The results of this study appeared to demonstrate that "when patients increase their attempts to control pain they also experience increasing difficulties, particularly with pain, psychosocial and other disability, anxiety and depression" (McCracken et al., 2007, p. 347). Vowles, McCracken, and Eccleston (2008) also found that greater acceptance was associated with better functioning.

Studies have consistently shown that contrary to what one may think, there has been a relatively low correlation between acceptance and pain intensity (Kratz, Davis, & Zautra, 2007; McCracken, 1998; McCracken et al., 1999). This means that increasing acceptance may be possible for all people with chronic pain, since it is not just a function of low pain levels. This fact-- as well as the data presented-- suggest that acceptance is associated with better adjustment to the chronic pain experience as a whole (McCracken, 1998).

2. **Barriers to acceptance**

There is more to acceptance than just accepting the pain itself. On top of dealing with pain and pain-related problems, people with chronic pain must also learn to

accept other factors that may be just as challenging. For instance, individuals with chronic pain are not only charged with accepting the pain, but also with accepting very real and fundamental changes to their identity that the pain has caused (Risdon et al., 2003). Moreover, societal values and common ideas about pain may contribute to people with pain being considered 'weak'. Moral and religious judgments such as 'Mankind is destined to suffer' and popular cultural sayings such as 'no pain, no gain' can contribute to people with chronic pain feeling pressured to 'suck it up' and push through, and their inability to do so ends up being understood as a failure (IOM, 2011).

Additionally, people with pain have to deal with the disbelief and stigma that often surrounds a chronic pain diagnosis. The IOM's report (2011) stated that "when pain could be ascribed to an underlying disease, such as cancer, it was accepted as real and treated with concern. The validation of disease made the pain socially acceptable, not shunned by the health care system or by families and communities" (p. x), but when a less well-defined condition that caused chronic pain was presented, "the lack of a defined disease made the symptoms of pain and suffering less acceptable and more ascribed to overreaction, emotional instability, or worse. Because the pain could not be seen or measured "objectively" or interpreted within the context of the known, it was more likely to be dismissed, diminished, or avoided" (p. x).

This is a common problem that people with chronic pain are confronted with. The fact of the matter is that pain cannot be measured, validated, or even proven.

Because of this, physicians can either believe their patients at face value or question the patient's report of pain (Reddy, 2006). The IOM's report explained this problem in health care.

Adequate pain treatment and follow-up may be thwarted by a mix of uncertain diagnosis and the societal stigma that is applied, consciously or unconsciously, to people reporting pain, particularly if they do not respond readily to treatment. Questions and reservations may cloud perceptions of clinicians, family, employers, and others: *Is he really in pain? Is she drug seeking? Is he just malingering? Is she just trying to get disability payments?* (2011, p. I-24)

This way of thinking goes back at well over two decades, but was illustrated in Vrancken's 1989 "Schools of thought on pain", which outlined different approaches to pain. The first, the somato-technical approach, separated pain patients into three groups: patients with real pain, psychiatric patients, and malingerers. The following is the description of the 'malingerer': "He may have a 'correct' story (at least partly correct) and there are historical clues suggesting that he may have real pain. Diagnostic procedures and treatment will continue, but then the patient will claim that the pain has not disappeared, although clinically it should have gone. Finally, the true state of the patient emerges: 'the actual diagnosis is that the patient seeks to profit by his pain'" (p. 436). According to this approach, the patient may have signs of real pain, but if the pain doesn't subside – as much chronic pain does not – they are thought to have ulterior motives. After discussing this problem as it currently stands, the IOM's report (2011) continued on to say that while there are certainly some patients who attempt to cheat the system for disability payments or drugs, data and studies have found that this number is small. However, this type of judgment and stigma is a constant struggle that people with chronic pain have to fight against.

In addition to pain not being provable or measurable, chronic pain in itself is invisible, meaning that others cannot 'see' that there is something wrong. People living with chronic pain are often not believed because they don't "look sick enough" (Mason, Skevington, & Osborn, 2004; Werner & Malterud, 2003). The question of belief was a common theme in Werner and Malterud's 2005 study of women with chronic pain. They found that "appearing ill and disarranged...risked being perceived as unable to manage. However, those who appeared as too healthy and smart, or in other ways as too strong, risked being assessed by the doctor as someone functioning well in their everyday life... Showing drive and determination nevertheless also seemed to conflict with the image of an 'ill' patient."

All of these issues present very real barriers to accepting chronic pain. Constantly being questioned, doubted, and told that the pain isn't real, it is easy to see how individuals with chronic pain might struggle with not only their diagnoses, but also the strategies they use to continue living their lives. Without having a clear idea of what the problem is, it is very difficult for it to be accepted. All of these barriers that society has created stand in the way of people with chronic pain accepting their situation and figuring out how to move forward.

3. Acceptance and commitment therapy

In recent years, a new therapy called acceptance and commitment therapy (ACT) has been developed. ACT seeks to change the function of negative psychological events and experiences and the individual's relationship to them (Hayes, Luoma, Bond, Masuda, & Lillis, 2006). Specifically, ACT helps patients focus on acceptance of negative experiences rather than focusing on control (Thorsell et al., 2011). The focus of

ACT is not on pain reduction, upon which many other therapies for people with chronic pain are based, but rather on participating in valued life activities despite the presence of pain. ACT "generally helps the participant to open up to, accept, and fully be in contact with the inevitable painful feelings, sensations or thoughts that arise as steps are taken out of avoidance patterns and back into life" (Thorsell et al., 2011, p. 721).

ACT has started to receive a lot of attention for chronic health conditions, including chronic pain, and the last decade has brought about quite a bit of research confirming its effectiveness. ACT-based therapy programs have been found to increase satisfaction with life, level of function, meaningful activity, willingness to experience pain, and to decrease depression, disability, and pain-related anxiety (Johnston, Foster, Shennan, Starkey, & Johnson, 2010; McCracken & Gutierrez-Martinez, 2011; Thorsell et al., 2011; Vowles & McCracken, 2008; Vowles, Wetherell, & Sorrell, 2009; Wetherell et al., 2011). Individuals who underwent an ACT-based treatment also used fewer sick days and fewer medical treatment resources than the control group (Dahl, Wilson, & Nilsson, 2004; Vowles & McCracken, 2008; Vowles, McCracken, & O'Brien, 2011). Although it is not a goal of ACT, Thorsell et al. (2011) found that participants in an ACT-based therapy program also experienced a decrease in pain intensity when compared with a control group. Many of these results were sustained over periods of time ranging from three months to three years (Dahl et al., 2004; McCracken & Gutierrez-Martinez, 2011; Vowles & McCracken, 2008; Vowles et al., 2011; Wetherell et al., 2011).

D. Other Variables

1. Pain characteristics

One of the characteristics of pain that may have an impact on QOL is *pain duration*. Data has been split on the impact of pain duration on QOL and related factors. Skevington (1998) found that patients with longer pain durations reported worse QOL. Kerr et al. (2004) found that longer pain duration was linked to reduced perception of general health and lower general health scores. Lee et al. (2008) found that pain duration contributed significantly to physical QOL scores. McCracken and Eccleston (2005) found a small negative relationship between pain duration and depression. However, many studies have found that pain duration does not have any significant impact on QOL or related factors (Borsbo, Gerdle, & Peolsson, 2010; McCracken & Gutierrez-Martinez, 2011; McCracken et al., 2004b; Skevington et al., 2001; Vowles & McCracken, 2008; Vowles et al., 2011).

The other pain variable that has been widely studied is the impact of *pain intensity* on QOL. While the reported impact has varied, most research has shown that pain severity does have an impact on QOL. Skevington (1998) found that the more intense evaluated pain was, the poorer participants reported their QOL to be. Laursen, Bajaj, Olesen, Delmar, and Arendt-Nielsen (2005) and Ainger et al. (2006) also found a significant correlation between pain intensity and the impairment of QOL. Becker et al. (1997) found modest but statistically significant correlations between pain intensity and health-related QOL. Esteve et al. (2007) and Turner, Jensen, and Romano (2000) found that pain intensity had a significant negative impact on pain, with Esteve et al. also finding a significant effect on levels of functional impairment. However, much of the

data has found that while pain intensity does have some impact on QOL and related factors, it has a much weaker impact than other variables (Kratz et al., 2007; Lame et al., 2005; McCracken & Eccleston, 2006; McCracken, Gross, Aikens, & Carnrike, 1996).

2. Catastrophizing

Catastrophizing can be described as an exaggerated negative "mental set" brought to bear during actual or anticipated pain experience (Sullivan, Rodgers, & Kirsch, 2001), or as a tendency to ruminate, magnify and feel helpless about pain (Sullivan, Bishop, & Pivik, 1995). The primary elements that make up catastrophizing are rumination ("I can't stop thinking about how much it hurts"), magnification ("I worry that something serious may happen"), and helplessness ("There is nothing I can do to reduce the intensity of the pain") (Sullivan, 1995). Catastrophizing has been associated with negative impacts on multiple areas of pain and QOL, even being related to a higher level of pain itself (Esteve et al., 2007; Sullivan et al., 1995; Sullivan et al., 2001; Turner, Mancl, & Aaron, 2004; Vowles, McCracken, & Eccleston, 2008; Wolff et al., 2008). Sullivan et al. (1995) found catastrophizing to have relationships with anxiety, feelings of sadness, and anger. Catastrophizing has also been correlated with emotional distress (Sullivan et al., 2001), worse mood (Turner et al., 2004), anxiety (Esteve et al., 2007), and depression (Richardson, Ness, Doleys, Banos, Cianfrini, & Richards, 2009; Turner et al., 2000), as well as functional impairment (Esteve et al., 2007) and higher disability (Arnow et al., 2011; Turner et al., 2004).

However, there have also been some contradictory findings. Turner et al. (2000) found that catastrophizing did not make significant contributions to prediction of physical disability. In two separate studies, Viane et al. (2003) also found that catastrophizing did

not have an effect on physical well-being. Vowles et al. (2008) found that acceptance of pain acted as a mediator on the effects of catastrophizing across measures of depression, pain-related fear, and disability. These studies suggest that while catastrophizing does have an impact on physical and emotional outcomes, these may not be direct products of catastrophizing (Vowles et al., 2008). Rather, there are other factors – such as acceptance – involved.

3. **Depression**

Cuijpers, van Lammeren, and Duzjin (1999) suggested that when a person experiences pain and also has another condition, the impact of the pain on QOL is worsened. One of the most prevalent comorbidity in people with chronic pain is depression. Estimates have varied, but Elliott, Renier, and Palcher (2003) found the prevalence of major depressive disorder in participants with chronic pain to be 52%, and Richardson et al. (2009) found that over two thirds of participants scored above the cut-off indicative of clinically significant depressive symptoms.

The relationship between chronic pain and depression and the impact of depression in individuals with chronic pain has been widely studied. Depression has been found to have several negative impacts on the QOL of people with chronic pain, including impacts on pain intensity (Haythornthwaite, Sieber, & Kerns, 1991; Sullivan et al., 2001), disability (Arnow et al., 2011; Borsbo et al., 2010), QOL (Ainger et al., 2006; Borsbo et al., 2010; Elliott et al., 2003), and general health (Borsbo et al., 2010). However, current research has shown that greater levels of acceptance are associated with lower levels of depression (McCracken, 1998; McCracken & Eccleston, 2003; McCracken & Zhao-O'Brien, 2010; Sullivan et al., 2012, Veehof et al., 2011).

4. Gender

While the relationship between chronic pain and gender is not completely understood, there is a growing body of research on the subject. While the numbers vary, multiple studies have shown that there is a higher prevalence of chronic pain conditions in women (De Moraes Vieira, Garcia, da Silva, Arauji, & Jansen, 2012; Munce & Stewart, 2007; Rustoen et al., 2004; Tsang et al., 2008). Women with chronic pain also report higher pain severity than men (Munce & Stewart, 2007; Rustoen et al., 2004), as well as higher levels of depression (Munce & Stewart, 2007), and more treatments (Rustoen et al., 2004). Also, women have reported higher levels of catastrophizing (Sullivan et al., 1995). On the other hand, men with chronic pain have reported a poorer QOL than women (Rustoen et al., 2004). Moreover, Pieh et al. (2012) found that women seemed to benefit more from a multimodal pain management program than men.

5. **Employment status**

Reports on employment within the chronic pain population are highly variable, but it is widely known that the population has a lower employment rate than the general population. For those people with chronic pain who are unemployed, there are numerous impacts on QOL that have been studied. Not working has been associated with depression in people with chronic pain. It has also been associated with poorer adjustment, more financial strain, higher pain intensity, and higher levels of emotional distress (Jackson, Iezzi, & Lafreniere, 1996). According to Jackson et al. (1996), "the unemployed chronic pain group tended to view their days as long, undifferentiated stretches of time, relatively devoid of meaningful activity, struggled to find occasions to use specialized skills and competencies, [and] had few novel experiences in their lives"

(Jackson et al., 1996, p. 364). It is understandable, then, that unemployment has been associated with reduced QOL in individuals with chronic pain (Gerstle et al., 2001; Wahl et al., 2009).

E. **Summary**

The purpose of this research is to find out whether there is a correlation between the level of pain acceptance and QOL in individuals with chronic pain. Participants will complete the revised CPAQ, the WHOQOL-BREF, the Pain Catastrophizing Scale (PCS), the Patient Health Questionnaire's 9-Item Depression Scale (PHQ-9), and a demographic survey to determine if levels of acceptance or any of the addressed covariants correlate with QOL.

Results of this study will hopefully lead to further research on acceptance and QOL in individuals with chronic pain. Additionally, results from the study can potentially help practitioners and professionals focusing on chronic pain to better understand the role of acceptance in chronic pain management.

F. Research Question

Is there a relationship between acceptance of chronic pain and QOL?

1. **Hypotheses**

- Acceptance:
 - (1) Individuals with higher levels of acceptance will report higher QOL.
- Pain Characteristics:
 - (2) Individuals who have been dealing with chronic pain for a longer duration will report a higher QOL.

- (3) Individuals with higher pain intensity will report a lower QOL.
- Catastrophizing:
 - (4) Individuals with a higher level of catastrophizing will report a lower level of acceptance and QOL.
- Depression:
 - (5) Individuals with depression will report a lower level of acceptance and QOL.
- ACT:
 - (6) Individuals who have received ACT will report higher levels of acceptance and QOL.
- Employment Status:
 - (7) Individuals who are unemployed will report lower levels of acceptance and QOL.
- Gender:
 - (8) Women will report higher pain intensities than men,
 - (9) Women will report higher levels of catastrophizing than men, and
 - (10) Men will report a lower QOL than women.

III. METHODS

A. Participants

This research studied individuals with chronic pain recruited through the US Pain Foundation's newsletter, the Chicago Chronic Pain Support Group's Meetup.com email list, and the Facebook pages of the U.S. Pain Foundation, the Chicago Chronic Pain Support Group, Surviving Chronic Pain, and Chronic Pain Info. The U.S. Pain Foundation (USPF) is a 501(c)(3) non-profit organization dedicated to serving those who live with pain conditions and their care providers. The mission of the USPF is 'to connect, inform and empower those living with pain while advocating on behalf of the entire pain community' (www.uspainfoundation.org). The Chicago Chronic Pain Support Group is a local peer support group for people dealing with pain conditions. Surviving Chronic Pain is an online peer-to-peer support group that also offers a 24-hour chat room for people to find the support they need. Chronic Pain Info is a Facebook group that is dedicated to providing information in a caring and understanding environment for patients, caregivers, and family members of people with chronic pain.

This research employed snowball sampling recruitment methods. Recruited participants were asked to forward study information on to other eligible individuals or groups of individuals in order to increase participation.

Inclusion criteria for participants included: being between the ages of 18 and 64, reporting musculoskeletal pain for at least 6 months, and living in the U.S. Exclusion criteria included not meeting the eligibility criteria.

A power analysis determined that the ideal number of respondents would be approximately 165. From the literature, we estimated that the R^2 for the full-model with

one primary predictor (acceptance of pain) and 8 control variables (age, gender, race/ethnicity, employment status, pain intensity, pain duration, catastrophizing, and depression) would be 0.3, with acceptance accounting for 5% of the variance and the other 8 variables accounting for 25% of the variance. Using an alpha level of 0.05, a total sample size of 150 would achieve 80% power to detect an R² increase of 0.05 when acceptance is added to the regression model. To account for an estimated 10% potential missing data from survey responses, that number was increased to 165 respondents. A total of 460 participants completed the survey, which was well above the required minimum.

B. **Procedure**

In October of 2013, an email was sent out to potential participants through the U.S. Pain Foundation and the Chicago Chronic Pain Support Group's email lists.

Facebook posts were also written by group administrators on the pages of the U.S. Pain Foundation, the Chicago Chronic Pain Support Group, Surviving Chronic Pain, and Chronic Pain Info. Representatives from the groups distributed information about the study (Appendix A) and a link to the online flyer (Appendix B) to their members. The online flyer included information about the study, eligibility requirements, instructions about snowball recruitment, and a brief description of the incentives for participation.

Participants then clicked on the link for the online informed consent and provided their consent before clicking on the survey link. The survey consisted of 88 rating and multiple choice questions and had an estimated timeframe of 15 to 30 minutes to complete. Once all of the responses were entered, participants submitted the completed survey by clicking on the "submit" link. Upon submission, participants were provided

with a list of resources (Appendix C), and they had the option to provide their email address so that they could have a chance to be randomly selected to win one of four \$50 gift card prizes.

The survey remained active for a period of two weeks. It was closed after 2 weeks because of the large number of responses already received. Completed responses were downloaded from Qualtrics to Microsoft Excel and were scored according to the scoring instructions of the individual questionnaires. The scores were then analyzed and using SPSS to see if the level of acceptance appeared to have an effect on QOL. Covariants were also analyzed and compared.

Federal regulations require that all research with human subjects be approved by the Institutional Review Board (IRB). The UIC IRB reviews research proposals to ensure that risks to participants are minimized and potential benefits are maximized. The IRB's ongoing oversight ensures that research subjects remain protected. This research was approved by the UIC IRB and complies with all IRB guidelines and recommendations.

C. Measures

Each participant completed the World Health Organization Quality of Life

Assessment- Brief version, the Chronic Pain Acceptance Questionnaire, the Pain

Catastrophizing Scale, the Patient Health Questionnaire's 9-Item Depression Scale, and a demographic questionnaire (copies of the instruments are included in Appendix D to H).

1. **Demographic questionnaire**

The demographic questionnaire (Appendix D) consists of 19 questions that were intended to gather background information such as age, gender, race/ethnicity, employment status, diagnosis, and pain characteristics (pain intensity, duration, and

location). Participants were also asked to provide a rating of their current pain levels (at the time they were completing the survey), as well as their pain levels in the past 24 hours and in the past week.

2. The World Health Organization Quality of Life Assessment- Brief version

The WHOQOL-BREF (Appendix E) is a 26-question instrument that is used to measure QOL. The main reason for the selection of the WHOQOL-BREF instead of the WHOQOL-100 is to minimize responder burden. Because of the debilitating nature of pain, some respondents may be too incapacitated to fully comply with an exhausting battery of measurements (Katz, 2002), and using the WHOQOL-BREF decreases the number of questions significantly. Decreasing responder burden may increase the number of respondents while also helping ensure more complete responses.

The WHOQOL-BREF was created to be a shortened version of the WHOQOL-100, which is an instrument that was developed by the WHOQOL Group in 15 international field centers. The WHOQOL Group comprises a group of collaborating investigators in each of the field sites and a panel of consultants. The WHOQOL-100 consists of 100 questions making up 24 facets that can be organized into four broad domains: physical, psychological, social, and environment (Table I). The WHOQOL-BREF uses one item from each of the 24 facets of the WHOQOL-100 as well as two items from the Overall Quality of Life and General Health facets (Von Steinbuchel, Lischetzke, Gurny, & Eid, 2006; WHOQOL Group, 1998) for a total of 26 items rated on one of four 5-point Likert scales. The resulting WHOQOL-BREF had high correlations

for domain scores with the WHOQOL-100, and Cronbach alpha values for each of the four domains demonstrated good internal consistency (WHOQOL Group, 1998). It was shown to be comparable to the WHOQOL-100 in discriminating between well and ill subjects, with significant differences between ill and well in all domains (WHOQOL Group, 1998).

TABLE IWHOQOL-BREF DOMAINS OF QUALITY OF LIFE

Domain	Facets incorporated within domains
1. Physical Health	Pain and discomfort; sleep and rest; energy and fatigue;
	mobility; activities of daily living; dependence on medicinal
	substances and medical aids; work capacity
2. Psychological	Positive feelings; thinking, learning, memory and
	concentration; self-esteem; bodily image and appearance;
	negative feelings; spirituality/religion/personal beliefs
3. Social Relationships	Personal relationships; social support; sexual activity
4. Environment	Freedom, physical safety and security; home environment;
	financial resources; health and social care: accessibility and
	quality; opportunities for acquiring new information and
	skills; participation in and opportunities for
	recreation/leisure activity; physical environment
	(pollution/noise/traffic/climate); transport

The internal consistency of the WHOQOL-BREF is good, with Cronbach's alpha consistently being greater than 0.7 (Ainger et al., 2006; Barros da Silva Lima, Fleck, Pechansky, De Boni, & Sukop, 2005; Berlim, Pavanello, Caldieraro, & Fleck, 2005; Garcia-Rea & LePage, 2010; Huang et al., 2006; Li, Kay, & Nokkaew, 2009; WHOQOL Group, 1998). Good test-retest reliability has also been found (Ainger et al., 2006;

WHOQOL Group, 1998). The WHOQOL-100 was shown to have excellent discriminant validity when discriminating between ill and well patients, and the WHOQOL-BREF has shown to be comparable in its ability (Garcia-Rea & LePage, 2010; WHOQOL Group, 1998). Discriminant validity has been significant for each domain (Ainger et al., 2006; Skevington et al., 2004). Berlim et al. (2005) and Li et al. (2009) found the WHOQOL-BREF domains to be significantly correlated with its overall QOL question, demonstrating good criterion validity. Construct validity is good, and while in Skevington et al.'s (2004) evaluation some of the items correlated with domains other than their intended domain, none of the items for the total sample correlated more strongly with another domain than with its own.

The WHOQOL-BREF has a possible range of scores of 26-130, with 26 questions each being scored from 1-5 and higher scores indicated better QOL. Three questions scores (3, 4, and 26) were reversed to transform negatively framed questions to positively framed questions. Total instrument and domain scores were then calculated. Scores were transformed to a 1-100 scale using instructions provided in the WHOQOL-BREF User Manual, which provided the formula:

Transformed Score = ((total score-lowest possible score)/range) * 100

3. The Chronic Pain Acceptance Questionnaire- Revised version

The CPAQ (Appendix F) consists of 20-items scored on a 7-point Likert scale that measure acceptance of pain. It includes two factors: (1) activity engagement, which is the pursuit of life activities regardless of pain, and (2) pain willingness, which is the recognition that avoidance and control are often unworkable methods of adapting to chronic pain (CPAQ- McCracken et al., 2004b). The original CPAQ was developed in

1992, and it included four factors: (1) engaging in normal life activities, (2) believing that controlling thoughts controls pain, (3) recognizing the chronicity of pain, and (4) needing to avoid or control pain. This four-factor structure was questioned and psychometrically evaluated by McCracken et al. (2004b), and findings supported a two-factor structure. A revised version of the CPAQ was suggested and subsequently created (McCracken et al., 2004b).

The revised version of the CPAQ has repeatedly demonstrated very good internal consistency with Chronbach's alpha well over 0.70 for the instrument (Bendayan, Esteve, & Blanca, 2011; McCracken & Velleman, 2009; McCracken et al., 2004b; Wetherell et al., 2011), as well as for the subscales (Costa & Pinto-Gouveia, 2011; McCracken & Velleman, 2009; McCracken et al., 2004b). The instrument has also demonstrated good construct validity (Bendayan et al., 2012; Mason et al., 2008; McCracken et al., 2004b).

The CPAQ has a possible range of scores of 0-120, with 20 questions each being scored from 0-6 and higher scores indicating higher levels of acceptance.

4. The Pain Catastrophizing Scale

The PCS (Appendix G) is a 13-item instrument designed to measure catastrophizing by asking participants to reflect on past pain experiences. Each of the 13 items is a thought or feeling that the respondent may experience when experiencing pain, and the respondent is asked to indicate the degree to which they have experienced them on 5-point scales from 0 (not at all) to 4 (all the time).

The PCS has been shown to have good internal consistency for the scale as a whole (Crombez, Eccleston, Baeyens, & Eelen, 1998; Severeijns, Van den Hout, & Vlaeyen, 2005; Sullivan et al., 1995; Turner et al., 2004) and adequate consistency for the

individual scales (Sullivan et al., 1995). The instrument has also demonstrated good test-retest reliability (Sullivan et al., 1995) and good construct validity (Sullivan et al., 1995; Turner et al., 2004).

The PCS has a possible range of scores of 0-52, with 13 questions each being scored from 0-4 and higher scores indicating higher levels of catastrophizing.

5. The Patient Health Questionnaire 9-Item Depression Scale

The PHQ-9 (Appendix H) is the 9-item depression scale of the Patient Health Questionnaire. It is based directly on the diagnostic criteria for major depressive disorder in the Diagnostic and Statistical Manual Fourth Edition (DSM-IV), and it is commonly used as a tool to assist in diagnosing depression (Kroenke, Spitzer, & Williams, 2001; Spitzer, Kroenke, Williams, & the Patient Health Questionnaire Primary Care Study Group, 1999). Items are scored from 0 to 3 and total scores can range from 0 to 27, with higher scores indicating more severe depression.

With only 9 items, the PHQ-9 has comparable sensitivity and specificity to other depression measures (Kroenke et al., 2001). The PHQ-9 has demonstrated excellent internal reliability with Cronbach's alpha consistently over 0.85 as well as excellent test-retest reliability (Kroenke et al., 2001). It has demonstrated criterion validity and construct validity, and it has been shown to discriminate well between individuals with and without major depression (Kroenke et al., 2001; Spitzer et al., 1999; Spitzer, Williams, & Kroenke, 2000).

The PHQ has a possible range of scores of 0-27, with 9 questions each being scored from 0-3 and higher scores indicating higher levels of depression. Scores correlate with a category of depression severity, with a score of 0-4 indicating no

depression, 5-9 indicating mild depression, 10-14 indicating moderate depression, 15-19 indicating moderately severe depression, and 20-27 indicating severe depression.

D. Data Collection

Participants who received information about the study were directed to a link to the Qualtrics survey site. Eligible participants provided their informed consent by clicking through to the survey (after reading the consent statement that appeared in the first frame (Appendix I), completing the eligibility screener (Appendix J), and completing the questionnaires mentioned above. As mentioned, the survey remained open for only two weeks due to the large number of responses. The study protocol was approved by the University of Illinois at Chicago's (UIC) Institutional Review Board (IRB) (Appendix K).

IV. RESULTS

A. <u>Data Preparation for Analysis</u>

Data was entered by the researcher in Statistical Packages for the Social Sciences (SPSS) version 21.0. All data preparation, univariate, and bivariate procedures were conducted using SPSS. After data entry, some item scores were reverse scored and the QOL subscale scores were all transformed on a scale of 0 to 100 according to the scale developers' instructions. The overall and subscale scores were then calculated for the required measures. Descriptive statistics, including frequency counts, means, variances, and scatter plots, were generated for all variables. Table II shows the descriptive characteristics of the participants, and Table III shows the descriptives (mean, standard deviations, and range) for the study variables.

TABLE IIDESCRIPTION OF PARTICIPANT CHARACTERISTICS

Variables and Categories	n (%)
Gender	
Male	35 (9.26%)
Female	343 (90.74%)
Race	
White	356 (94.18%)
Black or African American	4 (1.06%)
American Indian or Alaska	5 (1.32%)
Native	3 (1.32/0)
Native Hawaiian or other PI	2 (0.53%)
Other	7 (1.85%)
Prefer not to answer	4 (1.06%)
Employment Status	
Employed full-time	64 (16.93%)
Employed part-time	25 (6.61%)
Student	10 (2.65%)
Retired	13 (3.44%)
Unemployed due to	234 (61.90%)
pain/disabled	254 (01.7070)
Unemployed for another	19 (5.03%)
reason	, , ,
Other	13 (3.44%)
Pain Duration	
Between 6 months and 1	5 (1.32%)
year	` ,
Between 1 and 2 years	15 (3.97%)
Between 2 and 5 years	61 (16.14%)
Between 5 and 10 years	102 (26.98%)
Between 10 and 20 years	110 (29.10%)
More than 20 years	85 (22.49%)
ACT	244 (04 062 ()
No	344 (91.00%)
Yes	34 (9.00%)

TABLE III
DESCRIPTIVE STATISTICS FOR THE STUDY VARIABLES

			Scale		
Variable	Mean	St. Dev.	Range	Minimum	Maximum
Age	45.41	10.63	18-64	19	64
Average Pain	6.29	1.44	0-10	2	10
Catastrophizing	28.91	12.48	0-52	0	52
Depression	16.65	5.94	0-27	0	27
Total Acceptance	62.14	11.66	0-120	26	93

B. Bivariate Correlations

Bivariate analyses (correlations are shown in Table IV) were used to examine the relationships between all study variables. Several variables were significantly correlated with total QOL. Depression, catastrophizing, average pain level, and employment status were all significantly negatively correlated with QOL (r= -0.64 for depression, r= -0.49 for catastrophizing, r= -0.37 for average pain level, and r=-0.31 for employment status). Total acceptance was significantly positively correlated with total QOL, r= 0.39. Depression was significantly positively correlated with catastrophizing, r= 0.68, and average pain level, r= 0.31. Average pain level was also significantly positively correlated with catastrophizing, r= 0.29, and pain duration was significantly positively correlated with age, r= 0.26.

TABLE IV
BIVARIATE CORRELATIONS AMONG THE STUDY VARIABLES

	Age (19-64	Current Pain	Average Pain	Catastrophizing (0-52 possible)	Depression (0-27	Total Acceptance	Total QOL (0-
	possible)	(0-10 possible)	(0-10 possible)		possible)	(0-52 possible)	100 possible)
Age (19-64 possible)	1	-0.061	-0.091	-0.164**	-0.158**	0.005	0.116*
Current Pain (0-10 possible)	-0.061	1	0.883**	0.273**	0.274**	-0.009	-0.291**
Average Pain (0-10 possible)	-0.091	0.883**	1	0.290**	0.310**	-0.036	-0.365**
Catastrophizing (0-52 possible)	-0.164**	0.273**	0.290**	1	0.680**	-0.037	0494**
Depression (0- 27 possible)	-0.158**	0.274**	0.310**	0.680**	1	-0.133**	-0.639**
Total Acceptance (0- 120 possible)	0.005	-0.009	-0.036	-0.037	-0.133**	1	0.392**
Total Quality of Life (0-100 possible)	0.116*	-0.291**	-0.365	-0.494**	-0.639**	0.392**	1

^{*}*p* < 0.05

C. Multivariate Analysis

Hierarchical linear regression was conducted to predict QOL using acceptance of pain while controlling for average pain, catastrophizing, and depression. Age, gender, race/ethnicity, employment status, and pain duration were not included in the regression as controls because of very little variation in these variables among the participants. Further, none of these had a significant correlation with QOL. For the hierarchical regression as shown in Table VI, the following set of control variables was entered in the first block – average pain, catastrophizing, and depression. In the second block, acceptance of pain was entered as the predictor variable.

^{**}*p* < 0.01

The final regression model including rating of average pain experienced, catastrophizing, depression, and acceptance of pain explained 54.6% of the variance in QOL, with acceptance accounting for 10.8% of the variance (Table V). The final model with acceptance of pain as the predictor of QOL while controlling for average pain, catastrophizing, and depression, and their associated β and SE values, can be seen in Table VI.

TABLE VMODEL SUMMARY

					Change Statistics				
			Adjusted	Std. Error of	R Square				Sig. F
Model	R	R Square	R Square	the Estimate	Change	F Change	df1	df2	Change
1	0.665 ^a	0.442	0.438	10.37609	0.442	109.620	3	415	0.000
2	0.742^{b}	0.550	0.546	9.33030	0.108	99.244	1	414	0.000

a. Predictors: (Constant), Depression: 0-27, Average Pain: 0-10 possible, Catastrophizing:0-52

b. Predictors: (Constant), Depression: 0-27, Average Pain: 0-10 possible, Catastrophizing:0-52, TOTAL ACCEPTANCE 0-120

TABLE VI LINEAR EFFECT REGRESSION FOR THE PREDICTORS OF OVERALL QOL

	Unstandardized Coefficients				95.0% Confidence Interval for B	
Mode	el	В	Std. Error	Sig.	Lower Bound	Upper Bound
1	(Constant)	72.408	2.393	0.000	67.705	77.111
	Average Pain: 0-10	-1.714	0.369	0.000	-2.439	-0.989
	Catastrophizing:0-52	-0.107	0.056	0.056	-0.216	0.003
	Depression: 0-27	-1.207	0.119	0.000	-1.440	-0.974
2	(Constant)	46.783	3.353	0.000	40.191	53.374
	Average Pain: 0-10	-1.752	0.332	0.000	-2.404	-1.100
	Catastrophizing:0-52	-0.132	0.050	0.009	230	-0.033
	Depression: 0-27	-1.067	0.108	0.000	-1.278	-0.855
	TOTAL ACCEPTANCE: 0-120	0.391	0.039	0.000	0.314	0.468

Note: $SE = standard\ error$.

D. **Hypothesis Findings**

1. Acceptance of pain

With respect to acceptance of pain, the hypothesis was that individuals with higher levels of acceptance will report a higher QOL. As predicted, acceptance of pain was a significant predictor of QOL even after accounting for average pain, catastrophizing, and depression. Among the study participants, every unit increase in acceptance of pain was associated with a 0.39 unit increase in QOL (B= 0.39, p<0.001) over and above the control variables.

^{*}*p* < 0.05

^{**}*p* < 0.01

2. **Pain duration**

The related hypothesis was that individuals who have been dealing with chronic pain for a longer duration will report a higher QOL. This hypothesis was not supported such that pain duration had no significant relationship with QOL.

3. **Pain level**

Another hypothesis relevant to pain characteristics was that individuals with higher pain levels would report a lower QOL. This hypothesis was supported such that every unit increase in participants' ratings of their average pain experienced was associated with a 1.75 unit decrease in their QOL (B = -1.75, p < 0.001).

4. Catastrophizing

With respect to catastrophizing, the hypothesis was that individuals with a higher level of catastrophizing would report a lower level of acceptance and QOL. This hypothesis was partially supported. There was not a significant correlation between catastrophizing and acceptance. However, catastrophizing was significant negative predictor of QOL such that each unit increase in catastrophizing was associated with a 0.13 decrease in QOL (B = -0.13, p < 0.01).

5. **Depression**

The hypothesis was that individuals with higher depression scores would report a lower level of acceptance and QOL. There was not a significant correlation between depression and acceptance. However, as predicted, depression was a significant negative predictor of QOL such that each unit increase in participants' depression was associated with a one unit decrease in their QOL (B = -1.05., p < 0.001).

6. Acceptance and commitment therapy

The related hypothesis was that individuals who have received ACT would report higher levels of acceptance and QOL. This hypothesis is rejected as there was no significant correlation between ACT and acceptance and QOL.

7. Employment status

The hypothesis was that individuals who are unemployed would report lower levels of acceptance and QOL. In contrast, there was no significant relationship between employment status and acceptance of QOL for the sample.

8. Gender differences

With respect to gender differences, the hypotheses were that women would report higher pain intensities than men, women would report higher levels of catastrophizing than men, and men would report a lower QOL than women. All of these hypotheses were rejected. There were no significant gender differences found in any category.

V. DISCUSSION

A. Discussion of Findings

The purpose of this study was to determine whether acceptance of pain and several other variables impact the QOL of individuals with chronic pain. Specifically, I studied whether acceptance, age, gender, race/ethnicity, employment status, pain intensity, pain duration, catastrophizing, and depression had an impact on QOL.

1. Acceptance of pain

The finding in this study that individuals with higher levels of acceptance reported higher qualities of life is consistent with previous research (Esteve et al., 2007; McCracken, 1998; McCracken & Eccleston, 2003, 2005; McCracken et al., 1999; McCracken et al., 2007; Viane et al., 2003; Vowles et al., 2008) demonstrating positive outcomes related to increased levels of acceptance and suggesting that acceptance improves QOL. The impact of pain on an individual's life is far-reaching. It has been shown to affect physical, emotional, social, familial, and occupational functioning. Once an individual begins to accept the pain, they can also begin to better navigate their lives, spend less time and energy trying unsuccessfully to find a cure and more time and energy engaging in valued activities, and simultaneously continue to manage the pain using tools that have been proven effective. Keeping in mind that acceptance of pain is an ongoing behavioral process, the behaviors associated with this process – including willingness to experience pain and engagement in activities that are meaningful – have an enormous impact on the day-to-day QOL of individuals with chronic pain.

2. Pain characteristics

I hypothesized that individuals who have been dealing with chronic pain for a longer duration would report a higher QOL. Although some of the research said otherwise, I thought this would be the case because as the length of time an individuals experiences pain increases, they have more time to develop coping tools and find effective treatment methods to make the pain more manageable. However, this hypothesis was not supported. This study found no significant relationship between pain duration and QOL, which is consistent with other research (Borsbo et al., 2010; McCracken & Gutierrez-Martinez, 2011; McCracken et al., 2004b; Skevington et al., 2001; Vowles & McCracken, 2008; Vowles et al., 2011) that found that pain duration does not have a significant impact on QOL. However, my hypothesis and this finding is in contrast with some of the previous research (Kerr et al., 2004; Lee et al., 2008; Skevington, 1998) that found pain duration to have a negative impact on QOL.

I also hypothesized that individuals with higher pain levels would report a lower QOL. This hypothesis was supported, and this finding is consistent with other research (Ainger et al., 2006; Becker et al., 1997; Esteve et al., 2007; Laursen et al., 2005; Skevington, 1998; Turner et al., 2000) that demonstrated moderate to significant correlations between pain intensity and QOL. However, similar to other research (Kratz et al., 2007; Lame et al., 2005; McCracken & Eccleston, 2005; McCracken et al., 1996), this study found that pain level has a much weaker impact on QOL than other variables.

3. Catastrophizing

I hypothesized that individuals with a higher level of catastrophizing would report a lower level of acceptance and QOL. This hypothesis was partially

supported such there was no significant relationship between catastrophizing and acceptance, but catastrophizing was a significant negative predictor of QOL. The finding that there was no significant relationship between catastrophizing and acceptance is surprising. Behaviors associated with catastrophizing seem to be in stark contrast with behaviors associated with acceptance. However, as this finding illustrates, catastrophizing behaviors and acceptance behaviors are not mutually exclusive. The finding that catastrophizing is a significant negative predictor of QOL was expected and is consistent with previous research (Esteve et al., 2007; Sullivan et al., 1995; Sullivan et al., 2001; Turner et al., 2004; Vowles et al., 2008; Wolff et al., 2008) correlating catastrophizing with negative impacts on multiple areas of pain and QOL. This finding indicates that the more people ruminate, magnify, and feel helpless about their pain experience, the lower they report their QOL to be. Since QOL in was measured through a subjective questionnaire, it makes sense that an individual who frequently catastrophizes about their pain would report having a lower self-perception of their QOL.

4. **Depression**

The results of this study found that while there was no significant relationship between depression and acceptance, individuals with higher depression scores reported a lower level of QOL. This finding is consistent with previous research (Ainger et al., 2006; Borsbo et al., 2010; Elliott et al., 2003; Richardson et al., 2009) indicating that the more severe the depression experienced by the individual, the lower the individual's QOL. It is known that when a person is dealing with a second condition in addition to their pain, the impact of their pain on their QOL is worsened. With nearly two-thirds of this study's participants scoring in the moderately severely depressed or

severely depressed ranges, depression is clearly a prevalent and significant comorbidity in individuals with chronic pain. It stands to reason that when appropriate, receiving treatment for depression has strong potential to greatly improve the individual's QOL.

5. Acceptance and commitment therapy

I hypothesized that individuals who have received ACT would report higher levels of acceptance and QOL. This hypothesis is rejected, which contrasts previous research (Johnston et al., 2010; McCracken & Gutierrez-Martinez, 2011; Thorsell et al., 2001; Vowles & McCracken, 2008; Vowles et al., 2009; Wetherell et al., 2011) indicating a positive impact of ACT on aspects of QOL. This finding could be due to the fact that an overwhelming majority of participants had not participated in ACT. This seems to indicate that this practice is not widely used or available to people with chronic pain. Since there is a strong correlation between acceptance and QOL, further research into the effectiveness of ACT, whether it successfully increases levels of acceptance, and its impact on QOL is important.

6. **Employment status**

No relationship was found between employment status and acceptance or QOL. This was likely due to not having enough variation in the sample in terms of employment status.

7. Gender differences

I hypothesized that women would report higher pain intensities than men, women would report higher levels of catastrophizing than men, and men would report a lower QOL than women. All of these hypotheses were rejected. There were no significant gender differences found in any category. These findings were in contrast

with the small amount of research that has been done related to gender and chronic pain, which has demonstrated higher pain intensities in women than men (Munce & Stewart, 2007; Rustoen et al., 2004), higher levels of catastrophizing in women than in men (Sullivan et al., 1995), and lower reported qualities of life in men than women (Rustoen et al., 2004). A possible reason for this finding is that there was little variation in the sample, with an overwhelming majority of respondents being female.

B. Limitations

This study highlights the impact that the acceptance of chronic pain has on the QOL of individuals with chronic pain. It shows that even when controlling for several other potentially confounding variables, acceptance has a strong positive correlation with QOL. However, the study has several limitations. One limitation of this study is the sample population. The participants were self-selected, providing they met specific requirements, which may be reflective of specific personality types that were not able to be accounted for. The population was overwhelmingly female (90.74%), and it was also overwhelmingly white (94.18%). Additionally, the online nature of the surveys excluded individuals without internet access, which may make this study more reflective of individuals in certain income, education, or socioeconomic levels. Because of this, these results cannot be generalized to all individuals with chronic pain. While there is no way to control for this, it is important to note that pain is a subjective experience. Finally, each person's experience of pain, in conjunction with his/her own personal conditions or unrelated issues, is individual and cannot be easily compared to another's, and that is a limitation of this study.

C. Implications for Future Research and Clinical Implications

People with chronic pain are an under-recognized group, and it is important that research on chronic pain continue. The large response rate to this survey is evidence that many people with chronic pain agree. This study is in line with other research demonstrating a positive correlation between acceptance of pain and QOL outcomes. Because these findings illustrate that acceptance of pain may play a critical role in the lives of people with chronic pain, it is necessary to further explore the incorporation of acceptance-based approaches to chronic pain management. While ACT shows promise, it has made few strides in the chronic pain community, as evidenced by the low number of participants (9%) who had experienced it. Future research could use these acceptance-based approaches to determine causality of acceptance levels on QOL, either by focusing on an intervention with pre- and post-test measures or sampling from a larger pool of individuals with more people who have already had ACT or related therapies.

D. Conclusion

A majority of the findings from this study are consistent with other studies demonstrating positive outcomes related to increased levels of acceptance. However, this study is unique in that it correlates acceptance of chronic pain with overall reported QOL. This study also extends those results by focusing on other influential variables to determine their individual and combined impact on QOL. Even when controlling for the other variables, acceptance of pain was significantly positively correlated with QOL.

Chronic pain has been shown to reduce QOL more than almost any other condition, and many individuals spend much of their lives searching or waiting – unsuccessfully – for a cure. While it is important that people with pain continue those

on those that are not. The process by which individuals begin to accept their pain can enable people to live more fully. The findings of this study support that, and they are an important contribution to the chronic pain literature and practice in many regards.

Data continue to demonstrate that acceptance of pain is positively correlated with a better QOL, independent of other variables such as catastrophizing, depression, and pain level. For the many patients who are struggling daily with chronic pain, beginning the process of acceptance can have major implications. Rather than avoiding activity and being scared of the pain, acceptance allows individuals to regain some level of control over and participation in their lives. With the results of this and other similar studies illustrating the crucial role that acceptance plays in the QOL of individuals with chronic pain, it is imperative to begin to re-conceptualize our understanding of pain management and to begin to integrate acceptance-based approaches into mainstream chronic pain management programs.

APPENDICES

APPENDIX A

Announcement Texts

Email Text:

We wanted to let you know about a research study that is being conducted by a fellow person with chronic pain. Lindsay Baran is researching acceptance and quality of life in individuals with chronic pain as part of her thesis for her Masters in Disability and Human Development at the University of Illinois at Chicago (UIC), and she would appreciate your participation!

If you choose to participate, the link below will provide you with more information about the research study before clicking through to the survey. The survey should take you approximately 15-30 minutes and will ask you questions about your pain, your thoughts about pain, and your quality of life. If you decide to participate, you have the option of providing your email address at the end for a chance to win a cash gift card.

Please note that your participation in this research study is completely voluntary. Lindsay will not be collecting identifying information from the people who respond to the survey.

Also, in order to have as many participants as possible, please forward this survey link to anyone you know who may be interested in participating or spreading the word about this research study!

Please feel free to contact Lindsay with any questions at linbaran@uic.edu. If you have any questions about your rights as a research subject, including questions, complaints, or to offer input, you may call the Office for the Protection of Research Subjects (OPRS) at 312-996-1711 or 1-866-789-6215 (toll-free) or e-mail OPRS at uicirb@uic.edu.

Link to survey: www.ChronicPainStudy.webs.com

Newsletter/Facebook Text:

A fellow person with pain is conducting a research study on acceptance and quality of life in individuals with chronic pain. Find out more about her study and participate by taking the survey at www.ChronicPainStudy.webs.com.

Announcement Texts

Chicago Chronic Pain Meetup Group-specific:

Email Template:

Dear Chicago Chronic Pain Meetup Group Members,

I wanted to let you all know about a research study that I am conducting as part of my thesis for my Masters in Disability and Human Development at the University of Illinois

at Chicago (UIC). Largely due to my own experience with chronic pain, I have decided to focus on acceptance and quality of life in individuals with chronic pain.

I am reaching out to multiple chronic pain networks to try to get as many respondents as possible, and I would really appreciate your participation! Please note that **your participation in this research study is completely voluntary.** I will not be collecting identifying information from the people who respond to the survey.

If you choose to participate, the link below will provide you with more information about the research study before clicking through to the survey. The survey should take you approximately 15-30 minutes and will ask you questions about your pain, your thoughts about pain, and your quality of life. If you decide to participate, you have the option of providing your email address at the end for a chance to win a cash gift card. Also, in order to have as many participants as possible, please forward this survey link to anyone you know who may be interested in participating or spreading the word about this research study!

Please feel free to contact me with any questions at lnbaran@uic.edu. If you have any questions about your rights as a research subject, including questions, complaints, or to offer input, you may call the Office for the Protection of Research Subjects (OPRS) at 312-996-1711 or 1-866-789-6215 (toll-free) or e-mail OPRS at uicirb@uic.edu.

Link to survey: www.ChronicPainStudy.webs.com

Thank you. Lindsay Baran

Facebook post

Hi there! I would like to inform you of a research study that I am conducting on acceptance and quality of life in individuals with chronic pain for my Masters in Disability and Human Development. As a person with chronic pain, I am very interested to contribute to this growing field of research. Please click on the link below to find out more about this research study and participate by taking the survey. www.ChronicPainStudy.webs.com

APPENDIX B

Online Flyer (text)

This survey is part of a research study being conducted by a student with chronic pain who is pursuing her Masters in the Disability and Human Development department at the University of Illinois at Chicago (UIC). This research study focuses on chronic pain, acceptance of pain, and quality of life.

Your participation is voluntary and confidential. Participation in this research study involves filling out an online survey that will take approximately 15-30 minutes. The survey questions will be about your experiences with chronic pain, including questions about your pain, your thoughts about pain, and your quality of life. Once you have completed the survey, you will have the option to voluntarily provide your email address for the chance to receive one of four \$50 Mastercard gift cards.

In order to participate, you must meet the following requirements:

- (1) be between the ages of 18 and 64
- (2) reside in the US
- (3) be a person with chronic (>6 months) musculoskeletal pain. Musculoskeletal pain is pain in the bones, joints, muscles, or surrounding tissues. Musculoskeletal pain includes, but is not limited to, low back pain, tendonitis, fibromyalgia, arthritis, osteoporosis, and carpal tunnel syndrome.

In order to collect data from as many people with pain as possible, I am asking that you please forward information about this study to anyone you know who may be interested in participating or in spreading the word about this research study.

By clicking on the link below, you will be taken to the informed consent to participate in this research study.

Please contact Lindsay Baran, Principal Investigator, at lindsay lindsay Baran, Principal Investigator, at lindsay lindsay lindsay and fabricio@uic.edu if you have any questions about this research study, or if you have any questions, concerns or complaints. If you have any questions about your rights as a research subject, including questions, complaints, or to offer input, you may call the Office for the Protection of Research Subjects (OPRS) at 312-996-1711 or 1-866-789-6215 (toll-free) or e-mail OPRS at uicirb@uic.edu.

Thank you for your participation!

[Link to consent]

APPENDIX C

List of Resources

If you would like more information on chronic pain, or if you are looking to obtain crisis assistance or counseling, the following resources may be helpful to you.

National Chronic Pain Organizations

American Chronic Pain Association 1-800-533-3231 www.theacpa.org

National Fibromyalgia and Chronic Pain Association 801-200-3627 http://www.fmcpaware.org/

US Pain Foundation (800) 910-2462 www.uspainfoundation.org

Crisis Hotlines

National Suicide Prevention Lifeline: 1-800-273-TALK (8255) TTY: 1-800-799-4TTY (4889) www.suicidepreventionlifeline.org

National Hopeline Network: 1-800-SUICIDE (784-2433) www.hopeline.com

Online List of National and Local Suicide and Crisis Hotlines: http://suicidehotlines.com/national.html

APPENDIX D

Demographic Survey (text)
Age: (drop box: 18, 19, 2064)
Gender: (multiple choice: male, female)
Race: (multiple choice: American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, White, Other, Prefer Not To Answer)
Ethnicity: (multiple choice: Hispanic or Latino, Not Hispanic Or Latino, Prefer Not To Answer)
Country of residence: (open)
Employment Status: (multiple choice: employed full-time, employed part-time, student, retired, unemployed because of my pain, unemployed for another reason, other:)
Diagnosis: (open)
Is your pain: (multiple choice: constant, recurrent)
Any non-pain diagnosis: (open)
Number of pain locations: (open)
Pain location(s): (open)
Amount of time you have been dealing with your pain: (drop box: 6 months, between 6 months and 1 year, between 1 and 2 years, between 2 and 5 years, between 5 and 10 years, between 10 and 20 years, more than 20 years)
Have you ever received Acceptance and Commitment Therapy?: (y/n)

Demographic Survey (text)

What is your pain **right now**, on a scale of 0-10 with 0 being *no pain* and 10 being *pain* as bad as it can be?:

APPENDIX D. <u>Demographic Survey (text)</u>

(drop box: 0, 1, 2...10)

In the past 24 hours, what was the **least** pain you had, on a scale of 0-10 with 0 being *no pain* and 10 being *pain as bad as it can be*?

(drop box: 0, 1, 2...10)

In the past 24 hours, what was the most pain you had, on a scale of 0-10 with 0 being *no pain* and 10 being *pain as bad as it can be*?

(drop box: 0, 1, 2...10)

In the past week, what was the **least** pain you had, on a scale of 0-10 with 0 being *no pain* and 10 being *pain as bad as it can be*?

(drop box: 0, 1, 2...10)

In the past week, what was the **most** pain you had, on a scale of 0-10 with 0 being *no pain* and 10 being *pain as bad as it can be*? (drop box: 0, 1, 2...10)

What type of pain do you have? Check all that apply:

31 1 3		11 2		
(check boxes: throbbing, achin	ng, pounding,	shooting, pricking	ng, stabbing, sha	arp, dull
pinching, gnawing, cramping,	pulling, wren	nching, hot, cold,	tingling, itchy,	heavy,
tender, radiating, other:)			

APPENDIX E

World Health Organization Quality of Life Assessment- Brief version

WHOQOL-BREF

June 1997

U.S. Version



University of Washington Seattle, Washington United States of America

Emblem...Soul Catcher: a Northwest Coast Indian symbol of physical and mental well-being. Artist: Marvin Oliver

World Health Organization Quality of Life Assessment- Brief version

WHOQOL-BREF

About You

Before you begin we would like to ask you to answer a few general questions about yourself by circling the correct answer or by filling in the space provided.

1.	What is your gender	Male		Female	
2.	What is your date of birth?	D	/ay	Month /	Year
3.	What is the highest education you received?	Elem	e at all nentary s n School ege		
4.	What is your marital status?	Single Married Living as M	arried	Separat Divorce Widow	ed
5.	Are you currently ill?	Yes		No	
6.	If something is wrong with your health, what do you think it is?			illness/J	oroblem

3

APPENDIX E (continued)

World Health Organization Quality of Life Assessment- Brief version

Instructions

This questionnaire asks how you feel about your quality of life, health, or other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks. For example, thinking about the last two weeks, a question might ask:

	Ī	(Please circle the number)						
For office		Not at all	A little	Moderately	Mostly	Completely		
use		I		l l		1 1		
	Do you get the kind of support from others that	1	2	3	4	5		
	you need?							

You should circle the number that best fits how much support you got from others over the last two weeks. So you would circle the number 4 if you got a great deal of support from others. o

			(Please circle the number)				
For office		Not at all	A little	Moderately	Mostly	Completely	
use				ļ l			
	Do you get the kind of support from others that you need?	1	2	3	4	5	

You would circle number 1 if you did not get any of the support that you needed from others in the last two weeks. o

		(Please circle the number)					
For office use		Not at all	A little	Moderately	Mostly	Completely	
	Do you get the kind of support from others that you need?	1	2	3	4	5	•

World Health Organization Quality of Life Assessment- Brief version

Please read each question, assess your feelings, and circle the number on the scale that gives the best answer for you for each question.

		(Please circle the number)					
For office use		Very poor	Poor	Neither poor nor good	Good	Very Good	
G1/G1.1 1.	How would you rate your quality of life?	1	2	3	4	5	

	(Please circle the number)						
For office use		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied	
G4 / G2.3 2.	How satisfied are you with your health?	1	2	3	4	5	

The following questions ask about **how much** you have experienced certain things in the last two weeks.

			(Pleas	e circle the num	ber)	
For office use		Not at all	A little	A moderate amount	Very much	An extreme amount
F1.4 / F1.2.5	3. To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
F11.3 / F13.1.4	4. How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
F4.1 / F6.1.2	5. How much do you enjoy life?	1	2	3	4	5

World Health Organization Quality of Life Assessment- Brief version

				(Pleas	se circle the num	ber)]
For office use			Not at all	A little	A moderate amount	Very much	An extreme amount	
F24.2 / F29.1.3	6.	To what extent do you feel your life to be meaningful?	1	2	3	4	5	

				(Pleas	se circle the num	ber)	
For office use			Not at all	Slightly	A Moderate amount	Very much	Extremely
F5.2 / F7.1.6	7.	How well are you able to concentrate?	1	2	3	4	5
F16.1 / F20.1.2	8.	How safe do you feel in your daily life?	1	2	3	4	5
F22.1 / F27.1.2	9.	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks.

				(Plea	se circle the numi	ber)	
For office use			Not at all	A little	Moderately	Mostly	Completely
F2.1 / F2.1.1	10.	Do you have enough energy for everyday life?	1	2	3	4	5
F7.1 / F9.1.2	11.	Are you able to accept your bodily appearance?	1	2	3	4	5
F18.1 / F23.1.1	12.	Have you enough money to meet your needs?	1	2	3	4	5

World Health Organization Quality of Life Assessment- Brief version

		•		(Pleas	e circle the numb	ber)	
For office use			Not at all	A little	Moderately	Mostly	Completely
F20.1 / F25.1.1	13.	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
F21.1 / F26.1.2	14.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

			(Ple	ase circle the numb	er)	
For office use	ce	Very poor	Poor	Neither poor nor well	Well	Very well
F9.1 / F11.1.	15. How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how **good** or **satisfied** you have felt about various aspects of your life over the last two weeks.

		•		(Pleas	e circle the numb	ber)	
For office use			Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
F3.3 / F4.2.2	16.	How satisfied are you with your sleep?	1	2	3	4	5
F10.3 / F12.2.3	17.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
F12.4 / F16.2.1	18.	How satisfied are you with your capacity for work?	1	2	3	4	5

World Health Organization Quality of Life Assessment- Brief version

			(Please circle the number)						
For office use			Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied		
F6.4 / F8.2.2	19.	How satisfied are you with your abilities?	1	2	3	4	5		
F13.3 / F17.2.3	20.	How satisfied are you with your personal relationships?	1	2	3	4	5		
F15.3 / F3.2.1	21.	How satisfied are you with your sex life?	1	2	3	4	5		
F14.4 / F18.2.5	22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5		
F17.3 / F21.2.2	23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5		
F19.3 / F24.2.1	24.	How satisfied are you with your access to health services?	1	2	3	4	5		
F.23.3 / F28.2.2	25.	How satisfied are you with your mode of transportation?	1	2	3	4	5		

World Health Organization Quality of Life Assessment- Brief version

The follow question refers to **how often** you have felt or experienced certain things in the last two weeks.

			(Please	e circle the num	ber)	
For office use		Never	Seldom	Quite often	Very often	Always
F8.1 / F10.1.2	26. How often do you have negative feelings, such as blue mood, despair, anxiety, depression?	1	2	3	4	5
	neone help you to fill out Please circle Yes or No)	this	Yes		No	
How lo form?	ng did it take to fill out th	is .				

THANK YOU FOR YOUR HELP

APPENDIX F

Chronic Pain Acceptance Questionnaire

CHRONIC PAIN ACCEPTANCE QUESTIONNAIRE

Below you will find a list of statements. Please rate the truth of each statement as it applies to you. Use the following rating scale to make your choices. For instance, if you believe a statement is 'Always True,' you would write a 6 in the blank next to that statement.

0 Never true	1 Very rarely true	2 Seldom true	3 Sometimes true	4 Often true	5 Almost always true	6 Always true
2. My life 3. It's Ok 4. I would 5. It's not	e is going w to experien	ell, even the nce pain. rifice import for me to co	ough I have tant things introl my pa	chronic pai n my life to in in order t	n. control this handle m	-
 7. I need 8. There	to concentra are many ac a full life ev	tivities I do	when I feel	pain.		
10. Contro	olling my pa oughts and	ain is less in	nportant that	n any other		y life. ake important
 			_		-	è. er I'm doing
15. When 16. I will	my pain inc have better	creases, I ca	n still take c	are of my r	esponsibili	
18. My w 19. It's a g	d putting my orries and fo	ears about w	hat pain wi	ll do to me	are true.	se.
 life. _ 20. I have	e to struggle	to do things	when I hav	e pain.		

APPENDIX G

Pain Catastrophizing Scale

$\overline{\Psi}$	
1	Copyright © 1995 Michael JL Sullivan
	PCS-EN
Client No.:	Age: Sex: M() F() Date:
headaches, tooth	nces painful situations at some point in their lives. Such experiences may include pain, joint or muscle pain. People are often exposed to situations that may cause ss, injury, dental procedures or surgery.
below are thirteer pain. Using the f	in the types of thoughts and feelings that you have when you are in pain. Listed a statements describing different thoughts and feelings that may be associated with following scale, please indicate the degree to which you have these thoughts and are experiencing pain.
0 – not at all 1 -	- to a slight degree $2-$ to a moderate degree $3-$ to a great degree $4-$ all the time
Vhen I'm in pai	n
₁	I worry all the time about whether the pain will end.
2	I feel I can't go on.
3	It's terrible and I think it's never going to get any better.
4	It's awful and I feel that it overwhelms me.
5	I feel I can't stand it anymore.
6	I become afraid that the pain will get worse.
7	I keep thinking of other painful events.
8	I anxiously want the pain to go away.
9	I can't seem to keep it out of my mind.
10	I keep thinking about how much it hurts.
11	I keep thinking about how badly I want the pain to stop.
12	There's nothing I can do to reduce the intensity of the pain.
13	I wonder whether something serious may happen.

... Total

Updated 11/11

APPENDIX H

Patient Health Questionnaire 9-item Depression Scale

PATIENT HEALTH QUESTIONNAIRE (PHQ-9)

NAME:		DATE:		
Over the <i>last 2 weeks</i> , how often have you been bothered by any of the following problems? (use "\scrtw" to indicate your answer)	Hot a all	Septem days	Mare treat heat	Hearly avery day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much		1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
Thoughts that you would be better off dead, or of hurting yourself in some way	0	1	2	3
	add columns:		+	+
(Healthcare professional: For interpretation of please refer to accompanying scoring card.)	TOTAL, TOTAL:			
10. If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?			ot difficult at al omewhat diffici ery difficult ctremely difficu	ult

PHQ-9 is adapted from PRIME MD TODAY, developed by Drs Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke, and colleagues, with an educational grant from Pfizer Inc. For research information, contact Dr Spitzer at rls8@columbia.edu. Use of the PHQ-9 may only be made in accordance with the Terms of Use available at https://www.pfizer.com. Copyright ©1999 Pfizer Inc. All rights reserved. PRIME MD TODAY is a trademark of Pfizer Inc.

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APPENDIX H (continued)

Patient Health Questionnaire 9-item Depression Scale

Fold back this page before administering this questionnaire

INSTRUCTIONS FOR USE

for doctor or healthcare professional use only

PHO-9 QUICK DEPRESSION ASSESSMENT

For initial diagnosis:

- 1. Patient completes PHQ-9 Quick Depression Assessment on accompanying tear-off pad.
- 2. If there are at least 4 \(\strict{s} \) in the blue highlighted section (including Questions #1 and #2), consider a depressive disorder. Add score to determine severity.
- 3. Consider Major Depressive Disorder
 - —if there are at least 5 ✓s in the blue highlighted section (one of which corresponds to Question #1 or #2)

 Consider Other Depressive Disorder
 - -if there are 2 to 4 √s in the blue highlighted section (one of which corresponds to Question #1 or #2)

Note: Since the questionnaire relies on patient self-report, all responses should be verified by the clinician and a definitive diagnosis made on clinical grounds, taking into account how well the patient understood the questionnaire, as well as other relevant information from the patient. Diagnoses of Major Depressive Disorder or Other Depressive Disorder also require impairment of social, occupational, or other important areas of functioning (Question #10) and ruling out normal bereavement, a history of a Manic Episode (Bipolar Disorder), and a physical disorder, medication, or other drug as the biological cause of the depressive symptoms.

To monitor severity over time for newly diagnosed patients or patients in current treatment for depression:

- 1. Patients may complete questionnaires at baseline and at regular intervals (eg, every 2 weeks) at home and bring them in at their next appointment for scoring or they may complete the questionnaire during each scheduled appointment.
- **2.** Add up \checkmark s by column. For every \checkmark : Several days = 1 More than half the days = 2 Nearly every day = 3
- 3. Add together column scores to get a TOTAL score.
- 4. Refer to the accompanying PHQ-9 Scoring Card to interpret the TOTAL score.
- 5. Results may be included in patients' files to assist you in setting up a treatment goal, determining degree of response, as well as guiding treatment intervention.

PHQ-9 SCORING CARD FOR SEVERITY DETERMINATION

for healthcare professional use only

Scoring—add up all checked boxes on PHQ-9

For every ✓: Not at all = 0; Several days = 1; More than half the days = 2; Nearly every day = 3

Interpretation of Total Score

Total Score Depression Severity

0-4 None

5-9 Mild depression

10-14 Moderate depression

15-19 Moderately severe depression

20-27 Severe depression

APPENDIX I

Informed Consent

University of Illinois at Chicago

Research Information and Consent for Participation in Social Behavioral Research

Acceptance and Quality of Life in Individuals with Chronic Pain

You are being asked to participate in a research study. Researchers are required to provide a consent form such as this one to tell you about the research, to explain that taking part Is voluntary, to describe the risks and benefits of participation, and to help you to make an informed decision. You should feel free to ask any questions you may have to the researcher at the contact information provided below.

Principal Investigator Name and Title: Lindsay Baran, Student

Department and Institution: Disability at Human Development, University of Illinois at

Chicago

Contact Information: lnbaran@uic.edu Faculty Sponsor: Fabricio Balcazar

Contact Information: fabricio@uic.edu or 312-413-1806

Why am I being asked?

You are being asked to be a subject in a research study about acceptance and quality of life in individuals with chronic pain. You have been asked to participate because you have been experiencing chronic musculoskeletal pain for at least 6 months, are between the ages of 18 and 64, and reside in the U.S.

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future dealings with the University of Illinois at Chicago. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

Approximately 250 subjects may be involved in this research at UIC.

What is the purpose of this research?

Researchers are trying to learn more about the effect that acceptance of chronic pain has on quality of life.

What procedures are involved?

This research will be performed online. You will need to complete the online survey, which will take about 15-30 minutes.

APPENDIX I (continued)

Informed Consent

What are the potential risks and discomforts?

To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life. There is a small risk of a breach of privacy (others will know you are participating in research) and confidentiality (accidental disclosure of identifiable data), but all possible efforts will be made to avoid this.

Are there benefits to taking part in the research?

Taking part in this research study may not benefit you personally, but we [researchers] may learn new things that could help others in the future.

What other options are there?

You have the option to not participate in this study.

What about privacy and confidentiality?

No identifying information will be collected unless you voluntarily choose to provide your email address to participate in the raffle. Email addresses will be removed from the data prior to data analysis. Please remember that if you look at information about this study on Facebook, while Facebook may not share the specific data collected during this research, it does collect information regarding your online activities, as per the usage agreement you accepted to use Facebook, and will share this information with others, including advertisers.

Can I withdraw or be removed from the study?

If you decide to participate, you are free to withdraw your consent and discontinue participation at any time.

Incentive to participants:

At the end of the survey you will have the option of providing your email address to be entered in a raffle of four \$50.00 Mastercard gift cards. Participants will have an approximately one in sixty three (or 1.6%) chance of being selected if this study obtains all 250 expected participants. Winners will be contacted through email and will be asked to provide their name and address in order to receive this gift card. All emails and other identifying information will be deleted/destroyed after the incentives have been distributed.

Who should I contact if I have questions?

Contact the researcher, Lindsay Baran, at lnbaran@uic.edu or the Faculty Sponsor, Fabricio Balcazar, at fabricio@uic.edu or 312-413-1806.

- if you have any questions about this study or your part in it,
- if you have questions, concerns or complaints about the research.

APPENDIX I (continued)

Informed Consent

What are my rights as a research subject?

If you feel you have not been treated according to the descriptions in this form, or if you have any questions about your rights as a research subject, including questions, concerns, complaints, or to offer input, you may call the Office for the Protection of Research

Subjects (OPRS) at 312-996-1711 or 1-866-789-6215 (toll-free) or e-mail OPRS at uicirb@uic.edu.

Remember:

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

Consent:

I have read the above information. I meet the study's eligibility requirements and I agree to participate in this research study.

o I agree to participate in this research study.

APPENDIX J

Eligibility Screener

This eligibility screener will help to determine whether you are eligible to participate in this study.

- 1. What is your age? (MC: Under 18, between 18 and 64, over 64)
- 2. In what country do you live? (MC: The USA, Outside of the USA)
- 3. Do you have pain that has lasted at least 6 months? (MC: yes, no)
- 4. Do you have musculoskeletal pain? Musculoskeletal pain is pain in the bones, joints, muscles, or surrounding tissues. Musculoskeletal pain includes, but is not limited to, low back pain, tendonitis, fibromyalgia, arthritis, osteoporosis, and carpal tunnel syndrome. (MC: yes, no, I don't know)

If all criteria is met- participant will be allowed to access survey

If criteria is not met- participant will not be allowed to access survey and the following message will display: "Based on your responses, you are not eligible to participate in this study. If you think you have reached this message in error, please look over your responses and try again. If you have any questions, please contact the Principal Investigator, Lindsay Baran, at LNBARAN@uic.edu. Thank you."

APPENDIX K

IRB Approval

UNIVERSITY OF ILLINOIS AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice Initial Review (Response To Modifications)

September 17, 2013

Lindsay Baran Disability and Human Development 1651 Lamont St, NW Washington, DC 20010

Phone: (847) 212-5432 / Fax: (312) 413-1804

RE: Protocol # 2013-0682

"Acceptance and Quality of Life in Individuals with Chronic Pain"

Dear Ms. Baran:

Your Initial Review (Response To Modifications) was reviewed and approved by the Expedited review process on September 12, 2013. You may now begin your research

Please note the following information about your approved research protocol:

Protocol Approval Period: September 12, 2013 - September 12, 2014

Approved Subject Enrollment #: 250

Additional Determinations for Research Involving Minors: These determinations have not

been made for this study since it has not been approved for enrollment of minors.

Performance Sites:
Sponsor:
UIC
None

PAF#: Not Applicable

Research Protocol(s):

a) Acceptance and Quality of Life in Individuals with Chronic Pain (no date); Version 2;

Recruitment Material(s):

- a) Online Flyer; Version 2 08/06/2013
- b) Announcement Texts; Version 3; 09/05/2013
- c) Eligibility Screener; Version 1; 09/05/2013

Informed Consent(s):

- a) Consent; Version 2; 08/06/2013
- b) A waiver of documentation of informed consent has been granted under 45 CFR 46.117 and an alteration of consent has been granted under 45 CFR 46.116(d); minimal risk; electronic consent will be obtained at enrollment and an information sheet will be provided.

Phone: 312-996-1711 http://www.uic.edu/depts/ovcr/oprs/ FAX: 312-413-2929

APPENDIX K (continued)

IRB Approval

Page 2 of 3

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific category(ies):

(7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
07/03/2013	Initial Review	Expedited	07/05/2013	Modifications
		_		Required
08/08/2013	Response To	Expedited	08/15/2013	Modifications
	Modifications			Required
09/06/2013	Response To	Expedited	09/12/2013	Approved
	Modifications			

Please remember to:

- → Use your <u>research protocol number</u> (2013-0682) on any documents or correspondence with the IRB concerning your research protocol.
- → Review and comply with all requirements on the enclosure,

"UIC Investigator Responsibilities, Protection of Human Research Subjects" (http://tigger.uic.edu/depts/ovcr/research/protocolreview/irb/policies/0924.pdf)

Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 355-0816. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Alison Santiago, MSW, MJ IRB Coordinator, IRB # 2 Office for the Protection of Research Subjects

Enclosure(s):

- 1. UIC Investigator Responsibilities, Protection of Human Research Subjects
- 2. Informed Consent Document(s):
 - a) Consent; Version 2; 08/06/2013

APPENDIX K (continued)

IRB Approval

Page 3 of 3

3. Recruiting Material(s):

- a) Online Flyer; Version 2 08/06/2013
- b) Announcement Texts; Version 3; 09/05/2013
- c) Eligibility Screener; Version 1; 09/05/2013

cc: Tamar Heller, Disability and Human Development, M/C 626 Fabricio Balcazar (Faculty Advisor), Disability and Human Development, M/C 626

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VITA

NAME: Lindsay Baran

EDUCATION: B.S., Kinesiology, University of Illinois at Urbana-Champaign,

Urbana-Champaign, Illinois, 2005

M.S., Disability and Human Development, University of Illinois

at Chicago, Chicago, Illinois, 2014

PROFESSIONAL Qualified Intellectual Disabilities Specialist, Avenues to

EXPERIENCE: Independence, Niles, Illinois, 2005-2006

Project Coordinator, Center on Health Promotion Research for Persons with Disabilities, University of Illinois at Chicago,

Chicago, Illinois, 2006-2008

Disability Specialist, Disability Resource Center, University of

Illinois at Chicago, Chicago, Illinois, 2008-2013

Disability and Aging Specialist, National Council on Independent

Living, Washington, DC, 2014-present